



Better Support: Understanding the needs of family and friends when a loved one attempts suicide

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Acknowledgements

This report forms part of the Better Support Project. This project aims to investigate the experiences of family, friends and significant others who have supported someone who has attempted suicide, and to develop useful co- designed resources to support those care-givers.

The Better Support project is generously supported by the Ian Potter Foundation and the Grenet Merrin Foundation.

SANE Australia would also like to express thanks to those individuals with lived experience of attempted suicide and their families, friends and significant others who participated in this research.

A note on terminology

The academic literature typically uses the word 'carer' to describe those who support a person who has attempted suicide. However, not all friends, family, and significant others or care-givers identify with the term carer.

This report uses the terms 'care-givers', 'family, friends and significant others' and 'carers' interchangeably to represent those who are supporting a person who has attempted suicide. We acknowledge some individuals will identify more strongly with one term over another.

Executive summary

Project Overview

With funding from both the Grenet Merrin and Ian Potter Foundations, and support from academics based at the University of New England, SANE Australia has undertaken Better Support, a two phased project to explore the needs of families and friends supporting those who have attempted suicide. The project explored the impact of the experience on the person providing care, as well as their perception of the support they received, and the types of support they would have found helpful at the time.

Support after a suicide attempt is typically provided by both health professionals and families, friends and significant others. However, little is known about the impact of providing this support on a non-professional care-giver (Ghio et al, 2011).

In the **first phase** of the project (August 2017 to December 2018), a mixed method study was undertaken, aimed at answering the following questions:

1. What are the experiences of family, friends and significant others who support a loved one after a suicide attempt?
2. What resources, interventions or improvements would family, friends and significant others like to see in order to provide better support to someone who has attempted suicide?

An online survey exploring care-giving after a suicide attempt was conducted between 27 November 2017 and 5 February 2018.

Thirty-two semi-structured telephone interviews were also carried out and sought to understand:

- the care-giver role
- the impact of mental illness
- interactions with health services
- the support needs of care-givers and what may help others in a similar situation.

The **second phase** of the project involves the development and trial of resources to help provide "**Better Support**" to the families and friends of people who attempt suicide, and will be completed by June 2020.

Key findings

Caring for someone after a suicide attempt has a profound impact on the care-giver:

Impacts on the lives of care-givers can be emotional, financial and social. Many reported the need to fill the gap of professional care when the person returned home, and to maintain a high sense of vigilance, impacted upon their own wellbeing and their ability to fill their other roles and responsibilities.



That was the worst thing, is we couldn't make it better and we didn't know how to and we were just floundering around and trying to cope with everything and just ... we had no idea what we were doing...



Ava, metropolitan Tasmania, caring for a child



Our whole life has changed since October [when attempt occurred] and people have just assumed that I've gotten on with it. I've moved on. I'm okay but no, I'm actually quite traumatised by it.



Shae, regional New South Wales, caring for a child

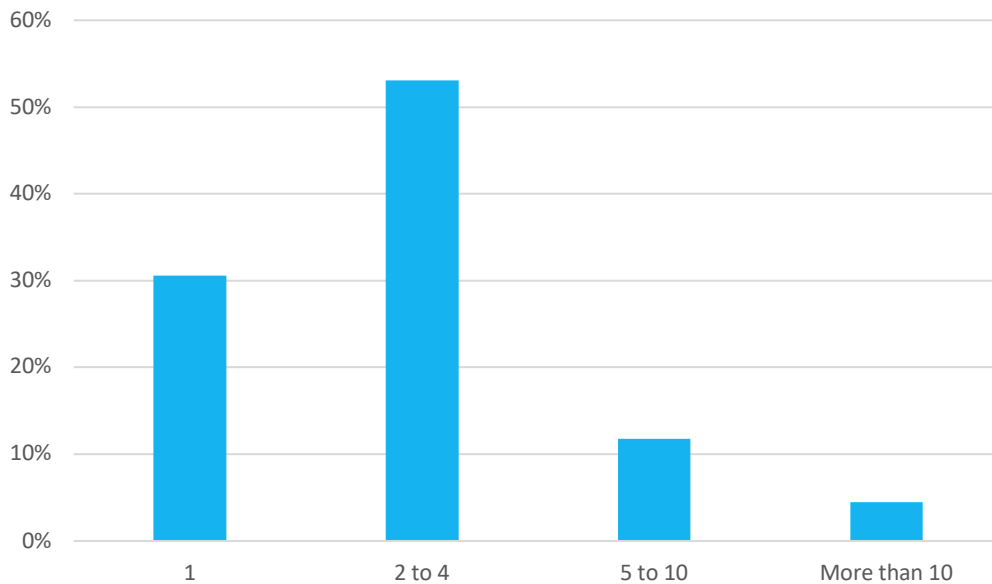
High number of survey respondents indicates care-givers want to be heard:

Over a two-month period, 834 people responded to the online survey, with a final sample of 758 who fulfilled eligibility requirements. Given the lack of research into the experience of care-givers of those at risk of suicide, this research provides important insights.

Many care-givers have experienced ongoing, crisis-driven responses, with multiple attempts at accessing professional help for the individual:

Approximately 9 in 10 participants indicated that the person who attempted suicide had a diagnosis of mental illness, with more than half indicating they believed the person had multiple diagnoses. More than two thirds of those who attempted suicide had done so more than once (Figure 1).

Figure 1: The number of times the person had attempted suicide (n = 695)



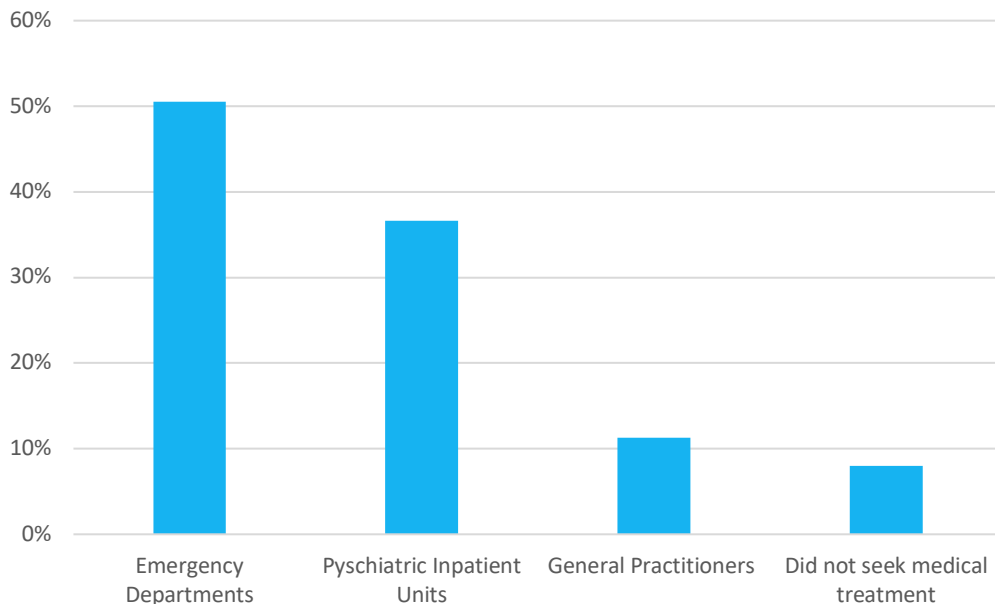
Care-givers are significantly more distressed than the general population, as measured on the K10 distress scale.

Forty-four percent of those who participated agreed that the suicide attempt of their loved one had 'a significant and devastating effect on my life that I still feel'.

9 in 10 participants reported that the person they were supporting required medical treatment as a result of their suicide attempt.

More than half – 50.5% accessed medical care via an emergency department; 36.8% via a psychiatric inpatient unit; and 11.3% via a general practitioner. 2.6% were unsure of the treatment provided. 8% reported that the person they were supporting did not seek medical treatment.

Figure 2: Medical treatment sought by the individual following a suicide attempt (n = 564)



When accessing care after the attempt, many participants felt the support offered to the person who attempted suicide was inappropriate or lacking.

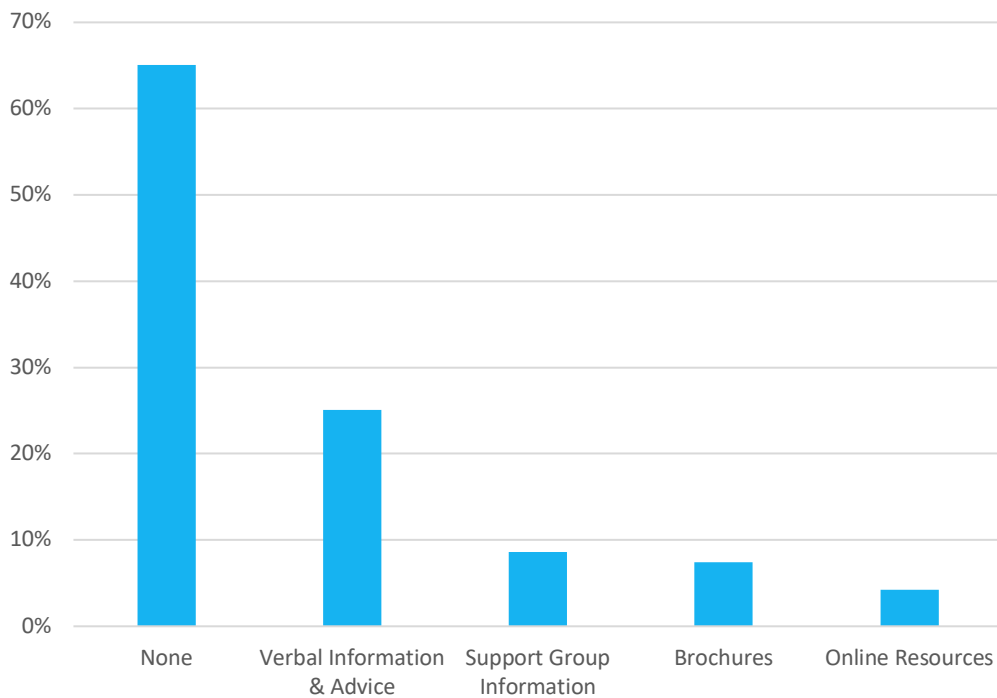
42.4% of participants reported the quality of the care provided to the person was poor or below average and only 27.9% of people rated the care provided as good or excellent (n = 589).

Participants did not feel they were adequately supported to care for the person they were supporting. More than half of respondents (56.2%) felt they were 'not well supported', or 'not at all supported' and only 18% felt they were supported or 'very supported' (n=649).

Furthermore, more than half (65.1%) of participants stated they did not receive any information about how to care for their loved one from the health professional treating the person who attempted suicide.

Only 25.1% were given verbal information and advice; a small group (8.6%) were given information on support groups; 7.4% were given a brochure; and 4.2% were given directions to online resources or factsheets.

Figure 3: Information reported to have been provided by healthcare professionals to care-givers (n = 570)



Carer-givers seek and want information, help and support from multiple sources.

Despite not receiving comprehensive information from health professionals about how best to care for their loved one, many people sought information from other sources including: online channels, via support groups, informal support from friends, or via individual psychological supports. Participants also discussed the value of talking to other people also caring for someone who had attempted suicide, and in finding peer-led information online.

Many care-givers found support groups to be beneficial, although, interestingly, these groups tended to focus on specific mental health diagnoses rather than suicide prevention per se. Nonetheless, they were still able to learn useful skills around crisis support and recognising suicidality.

Care-givers have clear ideas about how to improve support and information offered:

Participants frequently spoke about the need for acknowledgement, information and support for care-givers from health professionals. They described a need for better coordination between teams and services, and for increased training of health professionals around confidentiality and care-giver inclusion.

For example, one survey participant said:



Better liaison between the treating health professionals themselves, and for at least one of these people to liaise with me.



Survey Participant

Participants identified person-centred strategies as being most helpful for improving the support provided to care-givers. For example:



...someone who understood what I was going through and could give some advice. Knowing what to expect next.



Survey Participant

Respondents discussed the need for accessible, timely and affordable support, particularly immediately after discharge or during a crisis. They also highlighted that these services need to be more readily available to people in rural and regional areas.

Implications

1. Elevate the voices of people with lived experience:

The high participation rate of this survey demonstrates that care-givers are willing to share their experiences and contribute to change. A platform must be provided in order for the voices of those who care for people who have attempted suicide to be heard. Their expertise and contribution can play an essential role in suicide prevention.

There is potential to leverage this mostly unacknowledged support system as a key suicide prevention strategy, if care-givers are provided with better supports and their supports are more fully integrated into professional healthcare systems.

Recommendation One: Increase understanding within the healthcare sector about the crucial role that families, friends and other care-givers play in supporting people after suicide attempt, particularly where the individual has complex mental health needs. Encourage health professionals to listen, recognise and respect the expertise and experience of these care-givers.

2. Review of how services interact with care-givers:

Of particular concern is evidence collected during this study that indicated families are not being supported or included in discharge planning, and rarely have their own healthcare needs addressed.

This research suggests care-givers need to be provided easily-accessible information and resources about how to care for the person at home, and to be engaged in open dialogue, as co-designers, in the development of a discharge plan.

With the introduction of more after-care services seeking to engage with people who attempt suicide post-discharge, these and other healthcare service providers can also provide enhanced support to care-givers.

Recommendation Two: A review of the standard emergency department processes and practices after a suicide attempt in each state and territory in Australia. Care-givers must play a central role in developing recommendations for change and a clear roadmap for implementation of those changes.

Recommendation Three: A simple resource should be developed for staff in emergency departments and other healthcare settings to assist and improve how they respond to care-givers. This should provide practical information to help foster a culture of shared decision-making and collaborative engagement with care-givers to improve the care, support and treatment provided.

3. Address the lack of information for care-givers:

Care-givers need access to resources that provide holistic, practical, and accessible information at the time of crisis. For example, information that outlines the roles of peer support, community supports, emotional resilience, and provides tangible examples of how others have managed through lived experience storytelling.

Recommendation Four: The development of a care-giver resource – delivered by SANE as part of the Better Support project – that is practical, accessible and engaging.

Introduction

Suicide remains a significant public health issue in Australia. The latest figures show 3,128 people took their lives in 2017 (Australian Bureau of Statistics, 2018). Current literature reveals suicide is mainly preventable, and that those at greatest risk of dying by suicide are those who have made a previous suicide attempt (McKenna and Harrison, 2012). Targeting appropriate support towards those most at risk of suicide and self-harm is a cost-effective and meaningful way in which to reduce morbidity and mortality (McLaughlin et al., 2016). Providing appropriate care following a suicide attempt has been estimated to reduce suicide death by 1.1%–1.4% (Krysinska et al., 2015), and future attempts by 19.8% (Page, A., Atkinson, J, Heffernan, M., McDonnell, G., & Hickie 2017).

Specifically, the research acknowledges the important role that care-givers play in supporting someone who has attempted suicide (Van Orden et al., 2010). Their role can provide an important protective factor in reducing the risk of further suicide attempts and can help facilitate recovery. However, little is known about the impact of providing this support on the care-givers themselves, and how best to support them (Ghio et al. 2011).

People who provide care can experience adverse outcomes such as burnout, fatigue and a decline in their own health outcomes (McLaughlin et al., 2014). Providing information and support to these people at the time when the person they care for has attempted suicide, will be of benefit to their own wellbeing, as well as that of their loved one.

The Better Support project aims to investigate the experiences of family, friends and significant others who have supported someone who has attempted suicide. The project will explore the impact of the experience on the person providing care, as well as their perception of the support they received and the types of support they believe would have been helpful.

The first phase of the project used a mixed methods approach, incorporating a literature review, an online survey, and semi-structured interviews. The outcomes of this phase will guide the development of resources for people who are caring for someone who has attempted suicide to reduce care-giver burden and subsequent adverse outcomes.

About SANE Australia

SANE is a national mental health charity which aims to make a real difference in the lives of people affected by complex mental health issues.

There are over 800,000 Australians living with a complex mental illness, including schizophrenia, bipolar disorder, personality disorders, eating disorders, obsessive-compulsive disorder (OCD), post-traumatic stress disorder (PTSD) and severe depression and anxiety (Australian Government Productivity

Commission, 2019). For every one of these people, there will be at least five family members, friends, colleagues, or other people they know who are directly affected by their condition.

Over the past decade, as a nation, we have made great advances in reducing stigma around mild to moderate mental illness. Now, more than ever, people are seeking help, but there is still a great deal of work to be done to assist those at the more severe, or complex, end of the spectrum.

SANE's programmatic offerings include:

- A telephone helpline service operated by trained health professionals.
- The SANE Forums, online peer support forums, which enable individuals, families, friends, and care-givers to share their lived experience in a safe, anonymous and supportive environment.
- The SANE website, which provides resources and information for people affected by complex mental illness to help improve their quality of life.
- StigmaWatch, an online media centre, promoting the responsible portrayal of mental illness and suicide in the media and helping health professionals engage with the media.
- Policy and engagement programs, advocating for improved mental health and support services.
- The Hocking Fellowship, which promotes better mental health by advancing public understanding of mental illness.

About the Anne Deveson Research Centre

In 2018, SANE Australia established the Anne Deveson Research Centre (ADRC) to drive better social outcomes for Australians affected by complex mental health issues, their family, friends and colleagues.

The ADRC is unique in that it aims to bring together researchers from a range of backgrounds and disciplines within a non-government organisation (SANE Australia) – as well as other sector and industry partners – to explore these complex challenges in an inclusive and collaborative way.

Literature review

The impact of caring for someone at risk of suicide

Supporting a loved one or close friend who experiences a suicidal crisis can be one of the most challenging and stressful experiences. It has been shown to have a profoundly negative impact on the care-givers' own health (Chessick et al., 2007; McLaughlin et al., 2014), often described as 'care-giver burden'. This is defined as the 'objective and subjective effects of providing ongoing care to a person with an illness (Grant et al., 2015, p. 295). Objective burden includes observable direct impacts on the family such as financial strain, household disruption, increased physical responsibilities, and impaired interpersonal relations within the family and social network.

Subjective burden of caring for a person with mental illness may include painful feelings such as shame, stigma, grief, worry and resentment (Grant et al., 2015).

The impact of caring for someone with a mental illness has been documented since the 1950s. Literature detailing the impact of caring for someone at risk of suicide, however, has received less attention in the literature (Barksdale et al., 2009; Chiang et al., 2015; Grant et al., 2015). Whilst not everyone who attempts suicide has received a diagnosis of a mental illness, the majority of those at risk of suicide do, with reported rates between 43.8%–75.3% (Ferrari et al., 2014). Similarly, although not all people with a psychiatric diagnosis will experience suicidal thoughts or behaviours, certain diagnoses carry a higher risk of suicide than the general population (Chesney et al., 2014).

Whilst there is a strong link between mental illness and the risk of dying by suicide, there is evidence of an increased burden on those who provide care to loved ones exhibiting suicidal behaviour, compared to those who provide care to loved ones who have a mental illness but do not show signs of suicide risk. In addition to an increase in 'distress, burden and negative appraisal' (Katz et al., 2015, p. 797) when supporting a relative exhibiting harm against themselves, it was also found that caregivers who perceived a risk of harm to themselves or others experienced greater levels of objective burden, psychological distress, and poorer mental health (Katz et al., 2015).

Other research conducted by Chessick et al (2009), investigating suicidality and care-givers, found that care-givers rated suicidality as the most troublesome of a bipolar patient's depressive symptoms. A further American study, which involved the families of 90 people – all of whom had a diagnosis of schizophrenia – found that suicidal threats and gestures, while rare, were a significant predictor of increased family burden (McDonnell et al., 2003).

Despite the paucity of studies into the lived experience of care-givers of those at risk of suicide, there is a small body of work that has looked at these issues specifically. There are a number of studies that have measured care-giver burden for families caring for a suicidal person. They have reported increased psychological stress, poor physical health, and limits on their own activities due to caring responsibilities

(McDonnell et al., 2003; Chessick et al., 2007; Barksdale et al., 2009; Rajalin et al., 2009; Morgan et al., 2013; Katz et al., 2015).

McLaughlin et al (2014) used semi-structured interviews to investigate the experiences of 18 Irish families, all of whom looked after a family member experiencing suicidal ideation. They found all of the participants described the experience as 'hard work for the whole family' (2014, p. 236). The researchers categorised the responses into four sub categories: (i) family burden; (ii) competing pressures; (iii) secrecy and shame; and (iv) helplessness and guilt. All the participants reported that their physical and emotional health was compromised with the increased stress and hyper-vigilance that was required to keep their family member safe. Families also reported that the stigma surrounding suicide prevented them from (a) sharing their problems with others, or (b) that the suicidal family member did not want them to disclose what was happening within the family because of the shame and stigma they were experiencing. Families also felt helplessness and guilt, believing that they were not doing enough or had contributed to the situation in some way (McLaughlin et al., 2014).

These findings were similar to a Taiwanese study conducted in 2008 into the care-givers of those who had recently been released from in-patient care after a suicide attempt. Fifteen families took part in semi-structured interviews and described their experience as 'impending burnout' (Sun and Long, 2008, p. 1946). They felt they had to be on-guard day and night, whilst still maintaining the activities of daily living and creating a nurturing environment. These families also reported feelings of stigma and shame, and resorted to cultural explanations for the suicide attempts – these were attributed to 'bad luck', a 'kan-huo (hot energy) problem', or were played down as 'not a true suicide' (Sun and Long, 2008).

Stigma is a common theme across many of the studies, regardless of the country or culture. A Danish study into the parents of children who had attempted suicide found that the participants described feeling isolated after the suicide attempt, mainly because they were convinced nobody would be able to understand the horrible event. Some participants felt uncomfortable sharing their story because they felt shame (Buus et al., 2014).

These negative effects endure beyond the timespan of the suicidal crisis. Chessick et al (2007) found that past histories of suicide attempts were associated with lower levels of caregiver health even when suicidal ideation was absent or minimal among patients. This suggests that the suicide attempt of a spouse or family member has enduring effects on the care-giver, even years after the event.

The family member's relationship to the individual at risk of suicide may also impact the perceived burden experienced. Specifically, there is a greater proportion of research exploring the experiences of parents of adolescent or young children who are at risk of suicide. Chessick et al (2007) found that parents reported a greater level of role dysfunction burden than those who were caring for a spouse. However, this is in contrast to a Norwegian study that found there was no difference between spouses, parents and grown-up children in their level of concern that their loved one may attempt suicide (Buus et al., 2014).

A large American study by Barksdale et al (2009) found the care-givers of adolescents who had attempted suicide experienced similar objective strain (demands placed on their personal time, work time, and finances) as those caring for young people with a mental illness who were not suicidal. They also reported deleterious effects in family functioning, noting that their ability to monitor and set appropriate limits, or have age-appropriate expectations of their children, were compromised (Barksdale et al., 2009).

The literature investigated for this study also revealed the attitude of the care-giver to the person they were caring for affected family burden. Studies have found that where families hold negative attitudes or beliefs, there is an increase in care-giver burden (Sun et al., 2014; Katz et al., 2015). Furthermore, increased care-giver burden can increase the negative beliefs of the care-givers. Therefore, reducing care-giver strain can improve attitudes to those who need care (Chiang et al., 2015).

With the predominant findings suggesting extensive negative impacts, it is important to identify potential points of intervention – not only to benefit the health and wellbeing of the care-givers, but to also improve the experience of care received by those at risk of suicide.

Family involvement in treatment

Care-givers are consistently described in the literature as feeling unprepared, with inadequate knowledge to properly care for an unwell family member, and a lack of education about how to recognise signs of crisis (Grant et al., 2015). Caring for a relative at risk of suicide can elicit experiences of powerlessness and alienation, highlighting the gap in knowledge between mental health professionals and family members. For example, families have reported a lack of communication with healthcare providers following a suicide attempt by a loved one (Kjellin and Ostman, 2005; Cerel et al., 2006; McLaughlin et al., 2016).

One Australian study into the experiences of people living with bi-polar and their care-givers found that not being taken seriously by healthcare staff was the biggest challenge (McMahon and Lawn, 2011). This finding was echoed in a study of family members' experiences in an emergency department after the suicide attempt of a loved one (Cerel, et al., 2006). The study found more than half of consumers, and almost a third of family members, felt directly punished or stigmatised by staff. Consumers and family members also reported negative experiences involving perceived unprofessional staff behaviour, feeling the suicide attempt was not taken seriously (Cerel et al., 2006).

Contemporary approaches to suicide prevention suggest there should be a role for family and significant others in suicide treatment (Anastasia et al., 2015; Lawn and McMahon, 2015).

Theories that focus on social integration, psychological pain, burdensomeness, alienation, and hopelessness, demonstrate the need to build connections throughout the recovery process (Joiner Jr. et al., 2009; Van Orden et al., 2010; Anastasia et al., 2015). Family involvement in care serves as one of the cornerstones of the Suicide Prevention Action plan developed by Suicide Prevention Australia (2015).

When family members are actively involved in the recovery of their loved one, they can be a protective factor in preventing suicide attempts (Morgan et al., 2013; Grant et al., 2015; Chang et al., 2017). They often bring detailed contextual knowledge that can assist health professionals, and play an important role in maintaining the person's links to services, advocating for them when necessary (Barksdale et al., 2009; Grant et al., 2015; Nosek, 2008;).

People who have attempted suicide often recall that a sense of belonging to family helped them towards recovery (Anastasia et al., 2015). In a UK study of clients' views of suicide prevention, more than half of participants who had social supports available to them, reported that a family or friend was the 'most helpful factor' in suicide prevention efforts (Eagles et al., 2003, p. 823). Care-giver involvement in managing those at risk of suicide may, in fact, change the experience from one of powerlessness to one that can benefit both the care-giver and the person they care for (Grant et al., 2015).

Another common theme that emerged within the literature, is the lack of support offered to care-givers after their loved one has attempted suicide. Care-givers report a desire and need to be involved in the hospitalised care of their suicidal family member. However, some experienced exclusion when their family member was over 18 years of age, with issues of confidentiality often cited as a barrier (Lawn and McMahon, 2015; McLaughlin et al., 2016).

Families expressed a need to know more about warning signs and crisis management, and to receive information about suicidal behaviour and support (Byrne et al., 2008; Nosek, 2008; McLaughlin et al., 2016; Van de Bovenkamp and Trappenburg, 2018). They also found that whilst their family member was being cared for, healthcare staff did not recognize that care-givers also needed emotional support (Cerel et al., 2006; McLaughlin et al., 2016). They reported feelings of loneliness and isolation (Byrne et al., 2008; McLaughlin et al., 2016). Others talked of the difficulties experienced in accessing support for themselves, due to the necessity of being at home to provide care directly after a crisis (McLaughlin et al., 2016).

While there is some literature explaining difficulties faced by friends and families of people who attempt suicide, there is a significant gap – particularly in the Australian context. This gap limits understanding of what may help support people in their care-giver roles and prompted the Better Support research project.

Research methodology

Aims and objectives

This project aimed to answer the following questions, with regards to the Australian context:

- What are the experiences of family, friends and significant others who support a loved one after a suicide attempt?
- What resources, interventions or improvements would family, friends and significant others like to see in order to provide better support to someone who has attempted suicide?

A mixed method approach – defined as one that gathers both quantitative and qualitative data – was selected for the study. The quantitative data enabled the research team to examine the scale of the experience of caring for someone after a suicide attempt, and to understand the broader impacts of the care-giver role. The qualitative interviews enabled a detailed first-person account to add richness and a deeper understanding of the experience of supporting someone who has attempted suicide.

Ethical approval was sought via the University of New England's Human Research Ethics Committee, approval number HE17-210.

Quantitative research

An online questionnaire was designed by the project team, in consultation with a group of care-givers who had supported a person through suicidality. The survey was delivered via SurveyMonkey and consisted of 57 questions that gathered information on:

- participant demographics
- the relationship of the participant to the person who attempted
- their role as care-giver
- the impact of caring, as measured by the Care-giver Burden Scale (Macera et al., 1993)
- the mental health of the participant, as measured by the K10 psychological distress scale (Kessler et al., 2002)
- attitudes to suicide, measured by the Suicide Stigma Scale (Batterham, et al., 2013)
- the participant's interaction with health professionals
- support the participant received
- whether the person who attempted suicide had gone on to take their life
- changes the participant would like to see made to enable others to better support a person who has attempted suicide
- whether the participant would be interested in taking part in a telephone interview.

Survey procedure

The survey was promoted via the SANE Australia Facebook and Twitter accounts, and SANE's digital e-newsletter. It was also promoted through other Australian mental health and suicide prevention organisations. The survey opened on 27 November 2017 and closed on the 5 February 2018.

Eligibility and consent

Eligibility to take part in the survey required participants to be over 18 years of age, residing in Australia, literate in English, and to self-identify as having provided care to a person who had previously attempted suicide. Participants were also asked if they had supported a person around attempted suicide within the last ten years. Information about the project was provided at the start of the survey, and consent was sought as part of the survey structure.

Survey participants

A total of 834 people responded to the online survey. Five results were excluded as the respondents did not provide consent; an additional 14 were under 18 years of age; and 15 were excluded as they resided outside Australia. A further 42 were excluded as the respondent either identified that they did not know a person who had attempted suicide, or did not provide a response to this question, resulting in a final sample of N = 758.

Qualitative research

In order to provide more detailed data about people's experiences, the researchers sought to interview a sample from those who had participated in the online survey who had consented to further follow-up. The research team identified that a sample size of 30 semi-structured telephone interviews would provide saturation of lived experience reflections. The research team considered this number sufficient to identify a range of experiences, yet small enough to be feasibly collected within the study's timeline. A purposive sampling technique was used to ensure a balanced distribution of experience, gender, and geographic locations.

An initial interview schedule was formulated based on the issues present in the available literature. This interview schedule was then refined from the data received in the online survey. The review of the initial interview schedule occurred in March 2018 and a variation to the ethics submission was sought and approved, to account for the inclusion of new questions.

The resulting semi-structured interview schedule contained 42 questions that, in addition to collecting information on participant demographics and the relationship of the participant to the person who attempted, asked in-depth questions about:

- their role as care-givers
- the impact of caring
- their attitudes to suicide

- the participant's interaction with healthcare professionals
- support that the participant received
- changes that the participant would like to see to enable others to better support a
- person who has attempted suicide.

Interview procedure

Between April 2018 and August 2018, participants attended a telephone interview with either of the project's Associate Investigators, Sarah Coker or Dr Sarah Wayland. Participants were required to give verbal consent prior to the interview's commencement. Interviews lasted 45–90 minutes and were semi-structured, with the interviewer following the question schedule whilst allowing space for exploration of experiences as offered by the participant. Participants who experienced distress, or identified that they would like a follow-up phone call, were encouraged to contact their usual support networks, their treatment team, or were placed in contact with a SANE Helpline counsellor.

Interview analysis

All interviews were audio-recorded and transcribed verbatim. Data was uploaded into Nvivo software and coded by two members of the research team. The coded data was then re-checked for consistency and organised into main themes and sub-themes.

Quantitative results

Sample demographics

From the final sample (N = 758), 86.9% of participants identified as female, 10.7% as male, 0.7% as transgender and the remaining 1.7% as 'other'. Almost half of the participants stated that they were living in regional, rural or remote locations, which is higher than the population distribution – only a third of Australians live in rural, regional and remote locations. Only 2.5% of participants self-identified as being Aboriginal or Torres Strait Islander and 18.5% of participants indicated that they were born outside of Australia. A summary of the participant characteristics is provided below in Table 1.

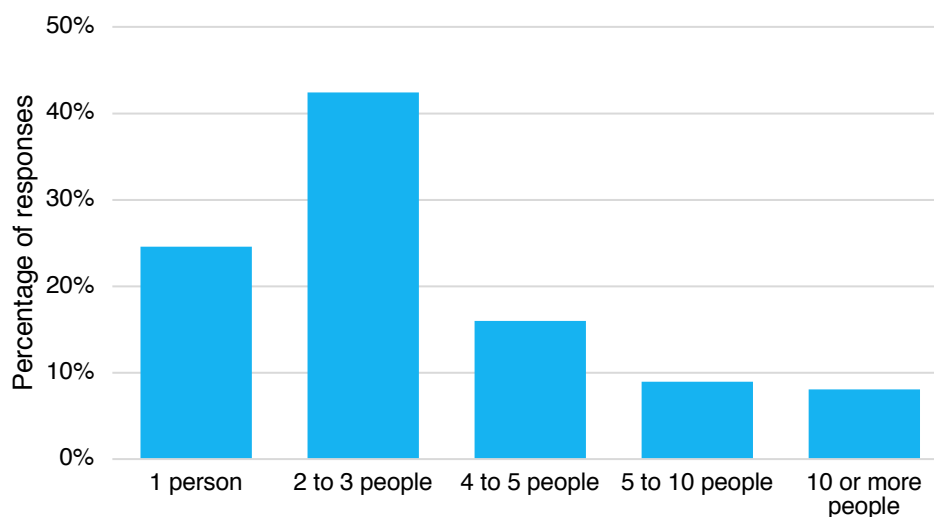
Table 1. Summary of survey participant characteristics (N = 758)

| Category | Sub-category | Frequency | Percentage |
|---|---|-----------|------------|
| Gender | Female | 659 | 86.9% |
| | Male | 81 | 10.7% |
| | Other | 13 | 1.7% |
| | Transgender | 5 | 0.7% |
| Country of birth | Born in Australia | 618 | 81.5% |
| | Born outside Australia | 140 | 18.5% |
| Indigenous Status | Aboriginal or Torres Strait Islander | 19 | 2.5% |
| | Not Aboriginal or Torres Strait Islander | 739 | 97.5% |
| Location | Metropolitan | 393 | 51.8% |
| | Regional | 242 | 32.1% |
| | Rural | 114 | 15.0% |
| | Remote | 8 | 1.1% |
| Relationship to the person who attempted suicide | Parent | 71 | 10.2% |
| | Family relation (cousin, aunt, grandparent etc) | 51 | 7.3% |
| | Child | 190 | 27.3% |
| | Friend | 176 | 25.3% |
| | Sibling | 45 | 6.5% |
| | Colleague | 10 | 1.4% |
| | Partner | 85 | 12.2% |
| | Other | 67 | 9.6% |

Participant exposure to suicide

This research aimed to understand who provides support to those who attempt suicide, and the level of exposure those care-givers have to the issue of suicide. Participants were asked how many people they knew who had attempted suicide. Results of the survey showed that more than three quarters of participants (75.4%) knew more than one person who had attempted suicide, with the average participant knowing at least two people who had attempted to take their own life.

Figure 4: The number of people that participants know to have attempted suicide (n = 757)

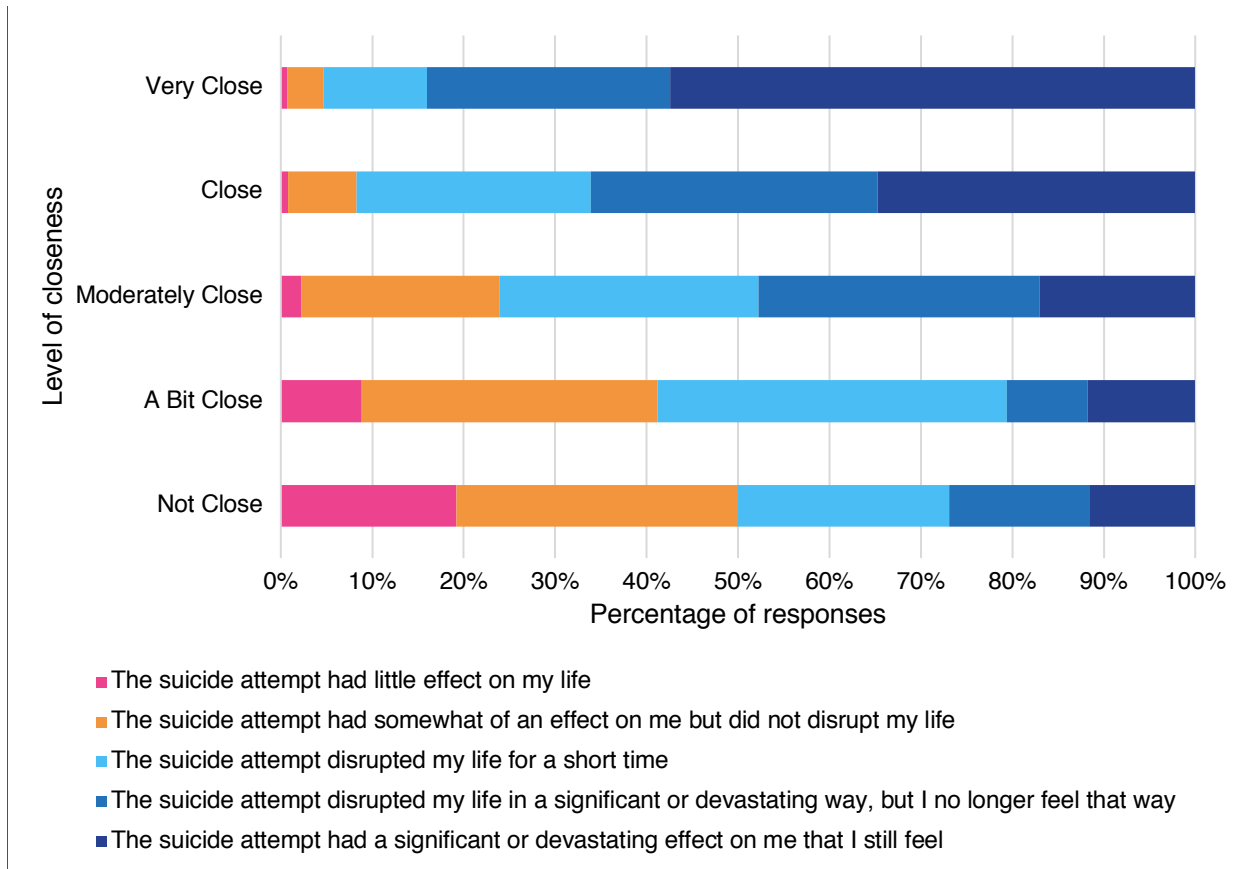


The survey asked people to think of the most significant person they had supported after a suicide attempt. The participants in this sample represented a range of relationships to the person who attempted suicide (Table 1). Most commonly, the respondent was a child of someone who had attempted suicide (27.3%), followed by a friend (25.3%). Partners were the next most commonly represented relationship (12.2%), followed by the parent of someone who had attempted suicide (10.2%), extended family (7.3%), sibling (6.5%), and colleague (1.4%).

The majority of participants (77.6%) rated their relationship with the person who attempted suicide as 'close' or 'very close', and most saw the individual who attempted suicide every day or every few days (71.1%).

With regards to impact, 44% of participants rated the suicide attempt as having 'had a significant or devastating effect on my life that I still feel'; and 26.7% rated the suicide attempt as having 'disrupted my life in a significant or devastating way, but I no longer feel that way'. Those who identified as 'very close' to the person who made the attempt, more frequently responded that the experience was 'significant or devastating' to the extent that they 'still feel' the effect (Figure 5).

Figure 5: Relationship between closeness to the person who attempted suicide and self-reported impact of the attempt (n=675)



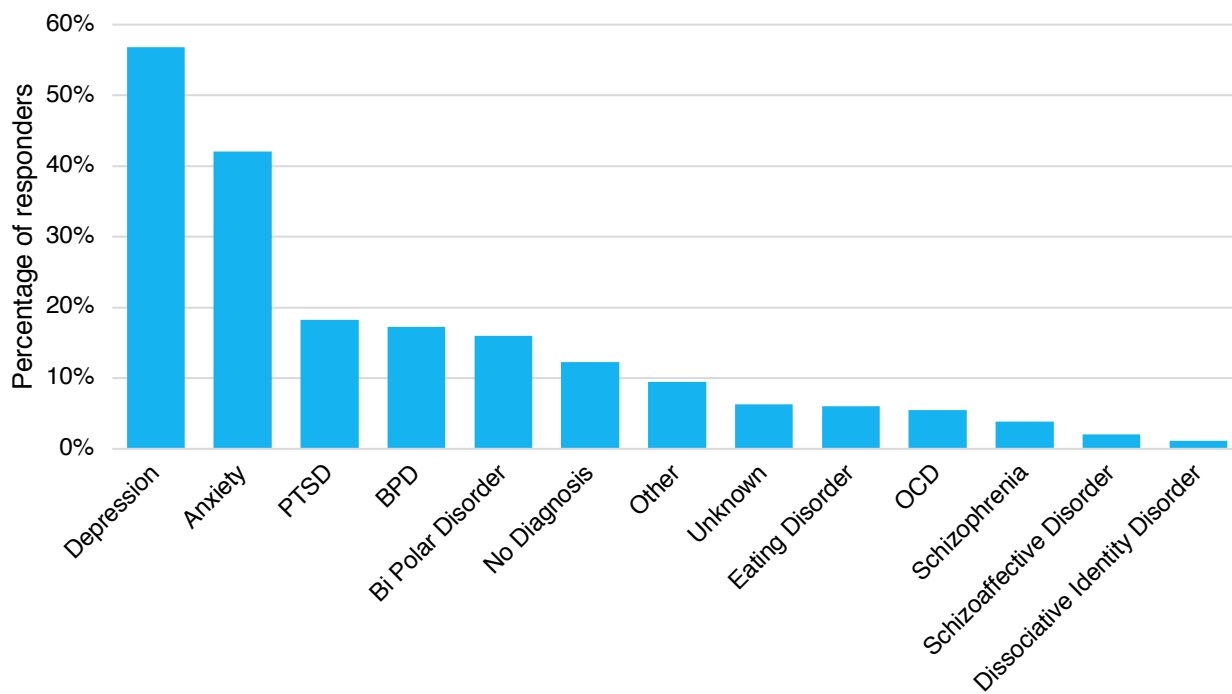
Profile of people who attempted suicide

Diagnosis

The researchers were interested to know about the person who had attempted suicide. This included determining whether the participant knew of any diagnosis of mental illness that the person who attempted may have had, as well as the frequency of their suicide attempts and whether they needed medical intervention after they had attempted suicide.

Figure 6 demonstrates that the majority of participants believed the person they were caring for had a diagnosis of mental illness, with only 12.2% of participants believing the person had 'no diagnosis'. The most common diagnosis was depression (56.8%) followed by anxiety (42%), and post-traumatic stress disorder (18.3%). Furthermore, just over half of participants (52.1%) indicated the person had multiple diagnoses. It should be noted that although a history of mental illness appeared to be common, this is based on indirect information and may not represent a formal diagnosis.

Figure 6: Diagnosis of person who attempted suicide as reported by the care-giver (n = 695)

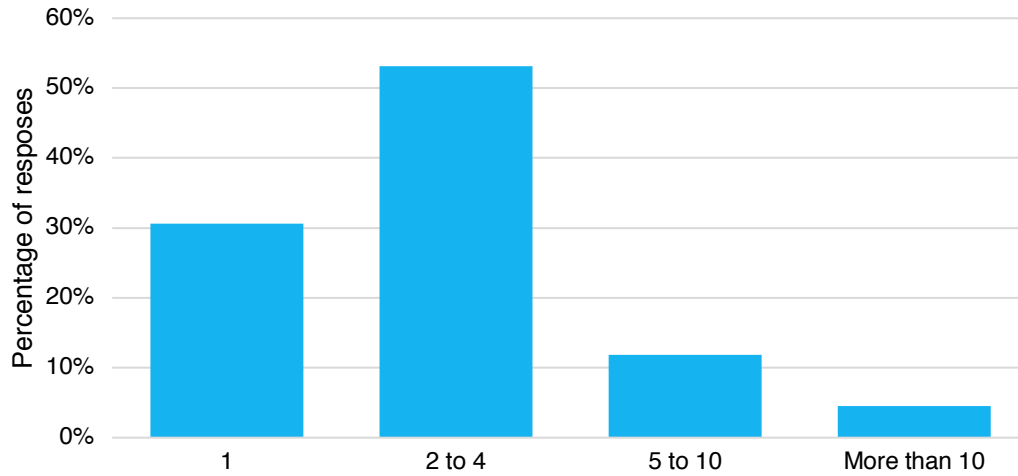


Number of suicide attempts

Participants were asked about the frequency of suicide attempts the person they were supporting had experienced 'to their knowledge'. This data showed that the majority of those who had attempted suicide had done so more than once, with 53.1% having attempted suicide between two and four times, 11.8% between five and ten times, and 4.5% more than ten times (Figure 7). Just under a third of people (30.6%) had attempted suicide only once.

It is worth noting that these figures are likely under-stated, as results for the interview stage showed that the participants frequently stated that they knew of a certain number of attempts but suspected there were other attempts that they could not confirm without certainty.

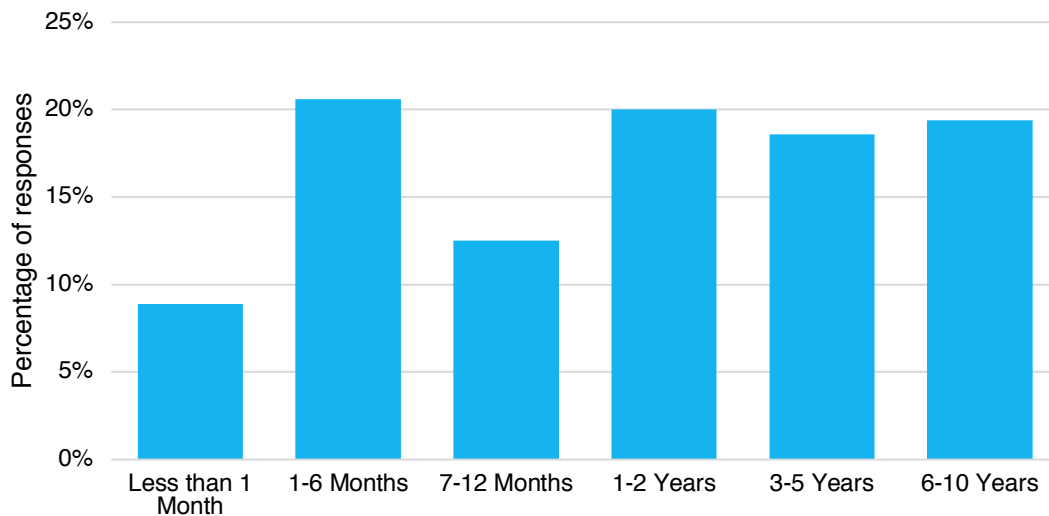
Figure 7: The number of times the person receiving support had attempted suicide, as reported by the participant (n = 695)



Time since last suicide attempt

There was considerable variation in terms of the time since the most recent suicide attempt had occurred. This could indicate that people were willing to contribute to the research regardless of how recently the suicide attempt had occurred. For nearly half of participants (42%), however, the experience was very current, with the most recent attempted suicide occurring in the previous 12 months. Figure 8 shows the length of time reported since the person's last suicide attempt.

Figure 8: Length of time since most recent suicide attempt (n = 695)



Engagement with the health system following suicide attempt

Following the suicide attempt, only a small number of participants (10.4%) reported that the person they provide care for did not require medical support afterwards. By comparison, 65% received care at an emergency department, 47.4% received care at a psychiatric in-patient unit, and 14.6% accessed care via their general practitioner. Given the high proportion of people accessing care at emergency departments and psychiatric in-patient units, there appears to have been considerable physical and psychological impacts on the individual.

Participants were asked to rate the quality of care that the person who attempted suicide had received using 5-point Likert scale with 1 = poor and 5 = excellent. This data revealed 42.4% rated the care as poor (rating = 1– 2) and 27.8% of participants rated the care as excellent (rating = 4– 5).

These ratings were then cross-tabulated by the type of care accessed and the proportion of 'excellent' to 'poor' ratings, to assess quality of care. These results were fairly similar across different types of care, with the perception of quality of care being slightly worse in emergency departments, slightly better in psychiatric in-patient units, and best when received from general practitioners, Table 2.

Table 2. Perceived quality of medical care after a suicide attempt, as rated by participant

| Type of medical care | Poor (1-2) | Neutral | Excellent |
|--|------------|---------|-----------|
| General practitioner (n=84) | 41.6% | 24.9% | 33.3% |
| Emergency department (n=376) | 45.2% | 24.2% | 28.4% |
| Psychiatric in-patient unit (n=276) | 43.4% | 25.5% | 30.6% |

Support provided to care-givers, family and friends

We asked participants about the support that they received to help them care for the person who attempted suicide, with a particular focus on whether they had received any information from the healthcare professional who treated the suicidal individual. Nearly half (65.1%) of participants stated that they did not receive any information from the healthcare professional who was treating the person who attempted suicide about how to care for their loved one. Furthermore, only 25.1% were given verbal information and advice; a small group of participants (8.6%) were given information on support groups for care-givers; 7.4% were given a brochure; and 4.2% were given directions to online resources or factsheets.

In terms of reaching out for help, around half of care-givers, families and friends did not seek any

professional support for themselves (32.5%). Of those who did, seeing a psychologist or counsellor was the most common form of support (28.2%), with general practitioners (14.8%), telephone helplines (7.1%) psychiatrists (6.8%) and social workers (4.5%) also being accessed to a lesser degree. It was reasonably common for care-givers, families and friends to turn to other friends and family for support (33.4%). Over a third (3.9%) sought information online to help in their support role (n = 649).

The survey also included short-answer response opportunities for people to expand on what would have made the provision of care or support more effective. Participants identified person-centred strategies as being most helpful in the provision of care. For example, *'someone who understood what I was going through and could give some advice. Knowing what to expect next', and 'more practical day to day support. It was emotionally exhausting so I lacked clarity a lot of the time in the weeks after.'*

Participants also described wanting to be included in the healthcare professional's understanding of the person's support network, as noted here: *'Better liaison between the treating health professionals themselves, and for at least one of these people to liaise with me.'*

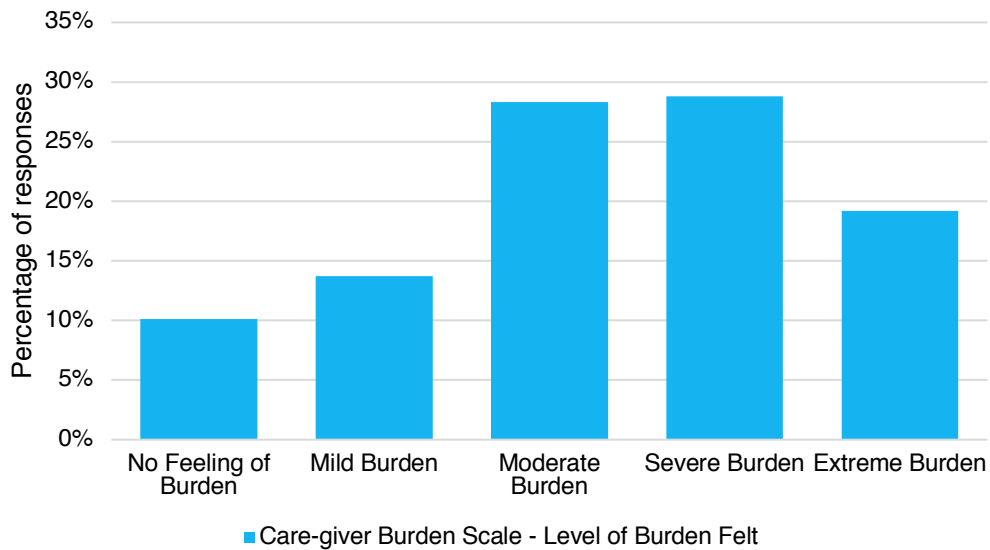
When asked about how adequately supported they felt to care for the person who attempted suicide, over half of participants (56.2%) felt they were 'not well supported' or 'not at all supported', and only 18% felt that they were 'supported' or 'well supported'.

Standardised tools included in the survey

Embedded within the survey were two standardised tools to assess care-giver burden and the current (last four weeks) global distress of the participants, measured by the Kessler-10 (K-10).

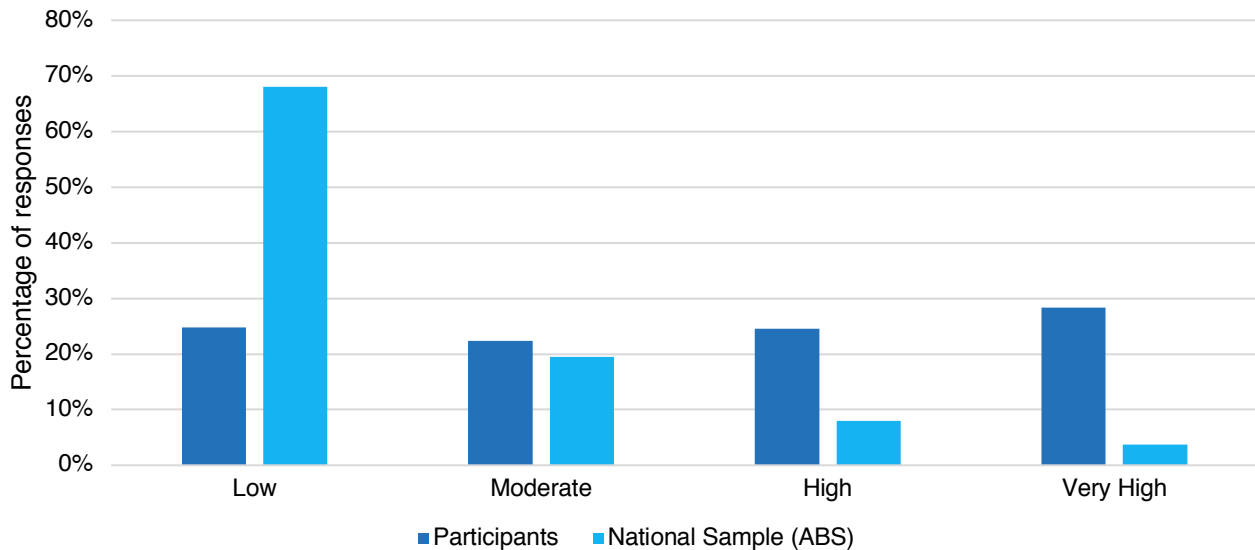
In relation to the Caregiver Burden Scale, a higher score represents the higher the level of burden the care-giver feels (Figure 9). Of the participants who responded (n = 527), a majority (76.3%) of participants reported a response which indicated they felt a moderate to extreme level of burdensomeness.

Figure 9: Care-giver Burden Measured through the Care-giver Burden Scale (n = 527)



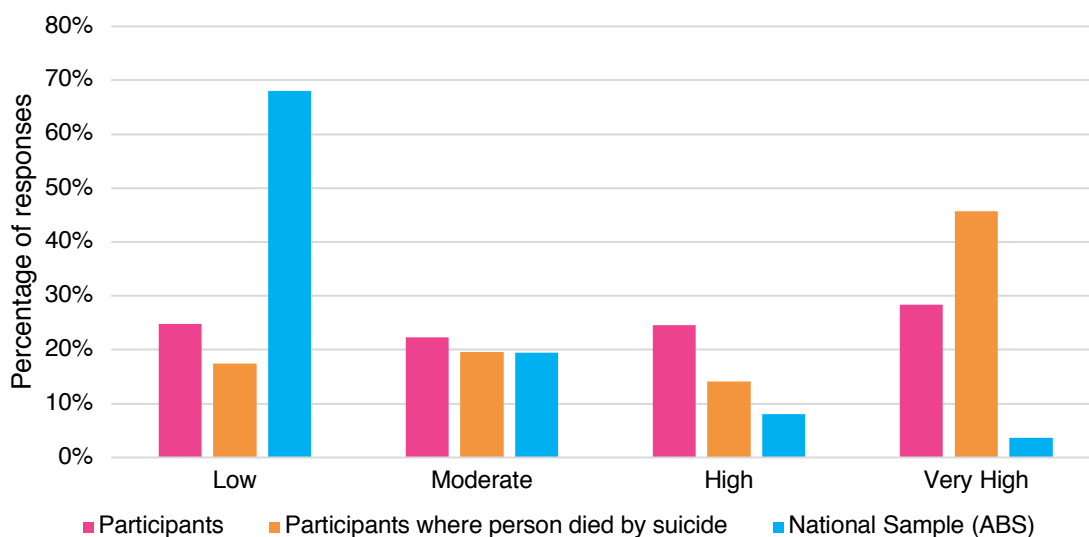
In relation to global distress as measured by the K-10, the participants of this survey were significantly more distressed compared to a nationally representative sample obtained via the Australian Bureau of Statistics (2015). More people in the survey sample reported high/very high distress ($p < 0.0001$). It should be noted that we cannot make a causal link between the participants' K10 scores and their specific experiences of care-giving, because the K10 focuses on the last 30 days. However, we can observe that participants in this sample were generally more distressed in comparison to the national average (Figure 10).

Figure 10: Comparison of distress, as measured by K-10 category of survey sample and nationally representative sample (n = 578)



Finally, we sought to understand the distress experienced by those who provided care where the person had gone on to die by suicide (12%, n = 92), compared with the rest of the sample and the general Australian population (again, via the K-10). When comparing the global distress scores of those who had experienced the suicide death of the person for whom they were providing care, a significant difference was observed when compared with both the total survey sample ($p < 0.0004$) and the Australian representative sample ($p < 0.0001$), Figure 11.

Figure 11. Distribution of K-10 scores for the complete survey sample (n = 578), participants who had cared for a person who had gone on to die by suicide (n = 92), and a nationally representative sample (ABS).



Summary

In summary, the quantitative survey data presents a picture of a wide variety of family members, friends, and significant others – the majority of whom were women – supporting a loved one through one or more complex suicidal crises. These care-givers typically feel a longstanding and extreme sense of distress when they have a close relationship to the person they are caring for. They do not feel well supported and most do not perceive the quality of care that the suicidal person has received to be of a high standard. As a group, they experience high levels of ‘care-giver burden’ and are significantly more distressed than the general population, especially if they have also been exposed to suicide bereavement. The following qualitative results will further unpack these themes and a subsequent discussion of the implication of these results will be presented.

Qualitative results

Interview participants

Interview participants were recruited via participation in the online survey. Of those who completed the survey, 242 indicated they would participate in an interview. From this group, eighty people were randomly selected to receive follow-up communication about being interviewed. Because the number of men responding to the survey was low (10.7%), men were preferentially chosen. Of those 80 people initially contacted, 35 people responded and 32 participated in an interview. Of the people who participated in an interview only two identified as being born outside Australia. These two people were British, indicating that this sample was not culturally diverse. This is summarised in Table 3.

Table 3. Summary of interview participant characteristics (N=32)

| Category | Sub-category | Frequency | Percentage |
|--|-----------------------|-----------|------------|
| Gender | Female | 24 | 75.0% |
| | Male | 8 | 25.0% |
| Ethnicity (as reported by participants) | Australian | 28 | 62.5% |
| | Indigenous Australian | 2 | 6.3% |
| | British Australian | 2 | 6.3% |
| State of residence | Victoria | 10 | 31.3% |
| | New South Wales | 10 | 51.3% |
| | South Australia | 6 | 18.6% |
| | Western Australia | 2 | 6.3% |
| | Queensland | 2 | 6.3% |
| | Tasmania | 2 | 6.3% |
| Location | Metropolitan | 16 | 50.0% |
| | Regional | 13 | 40.6% |
| | Rural | 3 | 9.4% |
| Relationship to the person who attempted (the participant was the persons...) | Parent | 14 | 44.0% |
| | Spouse/Partner | 6 | 18.8% |
| | Friend | 4 | 12.5% |
| | Child | 3 | 9.4% |
| | Extended family | 3 | 6.3% |
| | Health Professional | 1 | 3.1% |
| | Sibling | 1 | 3.1% |
| Had the person who attempted suicide gone on to take their life | Yes | 7 | 21.9 |
| | No | 25 | 78.1 |

Results – themes

The qualitative data revealed four main themes:

- Understanding the care-giver role: detailing the various ways in which participants would describe their care-giver role.
- The impact of mental illness on the person who was receiving care: reflecting the relationship between the suicide attempts and the fluctuating mental health status of the people being cared for.
- Interactions with health services: where participants would describe how they navigated the healthcare system as a means of accessing care and support.
- The support needs of care-givers: where participants shared knowledge about what is effective in terms of their own support needs and the kinds of information they access to do so.

A further area of focus within the interviews was investigating how participants thought services could be more effective and describing what ideal support might look like. These reflections, noted as 'future solutions' in the data will be used specifically as a means of directing the next stage of the project – resource development and recommendations.

Understanding the care-giver role

The interviews generated many insights of what is involved in looking after a loved one who has attempted suicide. These included the process of becoming a care-giver, an experience that for many people was the result of ongoing mental health needs, escalating crisis and instability.



In year eight she started refusing to go to school and this built up and built up over several weeks and in the end, she was referred to a psychologist at school. She was anxious and spent a lot of time at home, and by this time I'd actually left work so I was her carer.



David, metropolitan New South Wales, caring for his child

There were also many examples of the type of care provided to the person who has attempted suicide. These spanned from practical help (such as shopping and getting to appointments), financial support, emotional support (being there, listening and guidance) to very intensive crisis support that involved regular removal or distraction from means of suicide. These latter experiences were grouped under the term vigilance as a common experience of support people.

“

you're always keeping an eye out for him and then you've got the urge to hide everything sharp in the house. And then you realise how many sharp things are in the house. It was just ... yeah, it was horrible.

”

Ava, metropolitan Tasmania, caring for her child

“

There are definitely times where I won't leave her at home. Like if I have to be at Uni or if I've got a work shift, I'll organise someone to come and be with her.

”

Gary, regional Queensland, caring for his partner

“

Yeah and sometimes when he was really sick you know, I wouldn't get to sleep much because he'd say, 'I won't be here when you wake up in the morning' you know what I mean? I was like, 'I'll sleep with one eye open'..

”

Ashleigh, regional New South Wales, caring for her partner

Participants commonly described feelings of *isolation*, when they were left alone to care for the individual and had only limited support, if any, from others around them. This was partly driven by concern about what others would say (stigma), promises made to the individual that they would not tell anyone else about the attempt, or family circumstances that meant they were the only person available to help.

“

I've got no family members. I've got nobody. No mother, no father, no brothers and sisters, it's just me cause his father and his sister decided that they don't want nothing to do with this.

”

Maggie, rural South Australia, caring for her child

Although most of those being supported were accepting of the help being offered by the care-giver, there were also examples where the person did *not* want to accept help.

“

I never had any contact with (services) on his behalf but I certainly encouraged him to follow up and everything but he unfortunately ... you can't force a guy to get into a car and drive him up to an appointment and you can't force him to answer the door when an appointment comes to him.

”

Joe, regional South Australia, caring for his brother-in-law

Others described a complete *lack of confidence* in knowing what to do to help the person.

“

That was the worst thing, is we couldn't make it better and we didn't know how to and we were just floundering around and trying to cope with everything and just ... we had no idea what we were doing ...

”

Ava, metropolitan Tasmania, caring for her child

Guilt, grief and *trauma* were also common themes, particularly when friends, family or a significant other was also the first person on the scene immediately after the attempted suicide.

“

I spoke to our local GP and I said you know, why didn't I notice it was going to happen? Like I live with this man 24/7, you know I'm his carer ... so I feel like I've failed in my job because if I'm a carer, why would he do this? Because obviously I'm not caring for him well enough.

”

Emma, regional South Australia, caring for partner

“

Our whole life has changed since October and people have just assumed that I've gotten on with it. I've moved on. I'm okay but no, I'm actually quite traumatised by it.

”

Shae, regional New South Wales, caring for child

In fact, the *impact of supporting* a loved one after a suicide attempt was extensive and spanned from, having study and working commitments diverted – which lead to financial instability, through to social impacts – which included having to miss out on holidays and socialising with friends. This was in addition to the physical and mental health impacts that required ongoing treatment and support.

“

The whole episode has ... totally changed basically our lives, you know in that you can't plan a holiday. You know you don't know what your future's going to be and I think that's probably the sad part in how our lives have changed so much because we are ... we have grown up children. We should be at the stage, (where) we go okay let's take off a week here or there or stuff like that and let's go to a show or ... and that's just all basically gone and that's the impact that it's had on me you know and him.

”

Rose, regional New South Wales, caring for her partner

“

You know before that suicide attempt ... I was quite active in you know, my parish and the high school that my sons were at and I was co-chair of the high school board. I was teaching scripture. I was coordinating a sacramental program and I gradually had to give all that up and she got sicker and then I didn't have the emotional energy and then you look back and think, I can't imagine doing that anymore. I can't even imagine wanting to do that let alone being able to.

”

Selena, metropolitan New South Wales, caring for her child

As part of the caring role, participants talked about difficulties in *communicating with the person who attempted suicide* and feeling like they might say the wrong thing, make things worse or betray their trust.

“

I don't know exactly, you know because you're at that point where you're treading on eggshells and you're judging the mood you know. How much you're going to pry, you don't want him to run away and pack his bags and go...you know that sort of scenario I guess and he had asked me not to tell his brothers.

”

Ariana, regional Queensland, caring for her child

As described above, participants talked about the difficulties of navigating the care-giver role and the negative impact this could have on their ongoing relationship with the person they were caring for.

People also described the juggle of holding the *identity of being a care-giver* at the same time as being a wife, parent, or friend.

“

I'm still his wife you know like there's ... I'm still a thing happening here. I have an identity in this thing. I'm not just your carer. I have a ... I'm a person as well in this.

”

Sally, metropolitan Victoria, caring for her partner

The impact of mental illness

This theme reflected the complexity of the situations, both care-givers and those who attempted suicide were experiencing, and the relationship between the suicide attempts and the fluctuating mental health status of the people that were being cared for. For example:

“

My husband suffers Bipolar 2 so he has the dips but not the ups. And he was stable for about 20 years but in the last 18 months, he's been extremely unwell. His medication became ineffective and then he was put on a medication which was absolutely dreadful for him and it took a long time to convince the psychiatrist that it really wasn't a suitable medication for him. So you know part of his mental

”

illness has been that he's sort of formulated fairly complex ways to harm himself ...

Rita, metropolitan Victoria, caring for her partner

“

He suffers from schizophrenia and also chronic rheumatoid arthritis so he's (been) on a disability support pension since 2003. So I've been his primary carer for all this time you know, since he was diagnosed.

”

Emma, regional South Australia, caring for her partner

The ongoing mental illnesses people experienced also provided context for the frequent interactions with health services, and the frustration that developed when the person didn't receive the care their families and friends hoped to see.

“

She'd always just been anorexic but she developed bulimia as well, so she's now anorexic and bulimic and she's quite chronically ill now. She relapsed completely and she's just recently spent three weeks in (hospital) where she had to be rushed in through emergency because the electrolytes were dangerous.

”

Selena, metropolitan New South Wales, caring for her child

“

He'd been diagnosed with schizoaffective disorder ... They'd let him cease all his meds and two weeks before he actually died he started behaving quite erratically. I rang the service and said look, I don't know what's going on. I don't know when his next appointment with you guys is. When did he last have a depo shot? When's he due for the next one? And what's going on because he's not himself ...

”

Miranda, metropolitan Victoria, caring for her child

Although mental illness was mentioned frequently, it should be noted that *mental illness*, as a theme, may be over-represented in this sample because the recruitment of participants for the survey and the interviews was carried out by SANE Australia, a clearly-defined mental health charity focusing on the needs of people with complex mental health issues, and associated mental health networks. Nonetheless, it appears that when mental illness is experienced by the person being cared for, the impact can be particularly difficult for care-givers, not only because of ongoing fluctuating crisis, but also the experience of frequent interactions with services.

Interactions with health services

The analysis of the qualitative interviews revealed significant insights into what happened to the person who attempted suicide and the professional care they received. These insights ranged from the difficulties the person had in accessing support, to the quality of care and, in particular, the post-discharge support needs and the professionals who were treating the person who attempted suicide. Participants often felt they were well-placed to provide accurate information about the person's state of mind, but this was rarely taken into consideration.



How I've been treated and the trauma that I feel witnessing what's happening to my son and not having a voice cause suddenly you're voiceless when there's a crisis. Everybody else takes over and knows best and knows more and then of course when it's discharge time, they wipe their hands and suddenly I know and have to do everything. So, it's a complete reversal.



Shae, regional New South Wales, caring for child



I couldn't have any say in the Community Treatment Order at all, it was purely up to him. I didn't even know that they'd taken him off it until I rang his case manager trying to get some information on where had they transferred him to and it was almost out of spite that she told me that he'd been taken off the Community Treatment Order. And I'm ... 'well, when did somebody ask for my opinion?' 'Well, it's none of



your business. He's over 25 and don't need to discuss anything with you'.

Miranda, metropolitan Victoria, caring for her child



But yeah so in a case like that, when they haven't even asked me, what's happened beforehand? What's going on now? So, lack of consultation or even what do you call it? Don't take any value in what my observation was. I'm the one that's looking after her I'm the one that's supporting her ... yeah, I find it quite frustrating.



Gary, regional Queensland, caring for his partner

A number of participants talked about a *difficulty* in accessing what they viewed as appropriate care for the person they were supporting. The analysis of the interviews highlighted issues related to geographic availability of support services in rural and regional locations, a sense that there simply aren't enough services to cope with demand, or that the incident wasn't deemed serious enough to require care.



She got to like the ... emergency section where they just have curtains between patients while they're waiting to be admitted to a ward. So that's where she was for five or six days until we managed to get her a bed in the private facility ... and otherwise it was looking like she would be released from where she was without even being admitted or having any kind of psychological support.



Erin, regional South Australia, caring for her parent



I rang the mental health unit here in T which is the closest ... about 40 minutes away from where I live because we're in a rural area. You know, we couldn't get any help. They basically told me, unless he hurts someone or hurt himself, they couldn't do an assessment and I said he's declining. Something's



wrong, I know he's not okay and I'm really concerned about him.

Renee, regional NSW, caring for her child



I was furious at the hospital because they let him come home without any meeting with any of the psychological staff or mental health staff ... And they didn't even ask those questions and they virtually said like ... 'now you promise you won't do it again?' And he said, 'yeah I promise I won't do it again'. And he knows what it's like, he used to be a nurse so I'm sure he said that just to get out of hospital.



Emma, regional South Australia, caring for her partner

Almost all of the participants noted, with consistent identification, a *lack of post-discharge communication* as well as ambiguity around how much support would be offered. There seemed to be a consistent trend in participant feelings that confidentiality and the rights of the patient restricted the information healthcare professionals shared with the families, friends and significant others. This was particularly difficult for participants to fathom, given the potential seriousness of attempted suicide and their own fears and sense of responsibility as the primary support people outside of professional services.



There was a number of admissions last year when they let her go home far too soon. Like one of them was after a suicide attempt, they let her home after six days. The first five of those six days they were so concerned at the hospital she was on half hour checks. And then after day six she convinced the doctor she was alright and she was sent home and ... so yeah, I found that very frustrating. I wanted to have a plan, like the emergency action plan, safety plan, whatever you want to call it. What are we going to do when we get home? What's she going to do to occupy herself? What can I do? Just something that I requested and always it's basically no ... that's between B and the doctor, it's none of my business.



Gary, regional Queensland, caring for his partner

“

And like I said, you know they didn't even ask me to say that he's being released ... discharged and three days later when he was discharged from the public facility. We went in there and I spoke to the nursing manager and I said that it was done really poorly and I felt really out of the loop. As a care-giver I should've been involved in his discharge and that you know ... he's got a mental illness, it's not just up to him to be discharged. It's up to everybody else, who he's going to come home (to) ... who's going to have to look after him.

”

Jennie, metropolitan Victoria, caring for her partner

“

And at one stage we came in to see her and she was packing her bags to go. And I said, what are you doing? 'They've discharged me' and I've said, 'no they wouldn't have discharged you!' and I nearly had a fit and I ran outside to try and speak to somebody about it. No one would talk to me about it and eventually I had to ... you know, I broke down cried and yelled and they said to me ... 'have we got to go and get security and carry you away?' and I said, 'I just want someone to tell me what's going on'.

”

Gen, metropolitan Victoria, caring for her child

Another issue raised was a *lack of coordination* between different teams within a service or between services that impacted on the quality of care people received. Participants expected that departments *within* health services would speak to each other and would also pass on vital information to other health services who were involved the person's care.

“

You know, we've got a daughter in there who's packing up because she said, she's being discharged and it turned out that the surgical team ... the medical team or whatever discharged her without any consultation with the psychiatric team. She had

”

three teams looking after her and obviously none of them talking to each other and none of them knew what was going on and like I just thought that was unbelievably horrific.

Gen, metropolitan Victoria, caring for her child



When we finally saw the psychiatrist, she didn't even know this has happened because she said, 'how're you going' and I said 'well after what's happened we're not too bad'. And she goes 'why, what's happened?' And I said, 'have you not heard from the hospital?' ... cause she's a private psychiatrist and she said because it's not a private hospital, she said there's no communication and she had nothing ... no reports, nothing and then when he was discharged on the Sunday I rang his mental health nurse on the Monday and they hadn't ... she hadn't been notified at all that anything had happened.



Emma, regional South Australia, caring for her partner

Although the above paints a less than ideal view of the interactions care-givers and people who attempt suicide have with the health care system, this was not everyone's experience. Some had *positive experiences with healthcare*, and described supportive working relationships with the health care team that allowed them to provide good support for the person who attempted suicide, and to also seek support for themselves.



Like you know, any sudden medication issue or if there was a behavioural issue, not that there has been but anything like that, but, they're (the treating team) very good supporting me ... giving me the feedback I need.'



Interviewer: That sounds good. So, you've got the confidence then that there is somebody there should you need it?

'Yes.

Rose, regional New South Wales, caring for her partner

“

Yeah well look, the ... the psychiatrist and the psychologist that were treating C for that ... I suppose it was almost a three-year period. They were fantastic. We couldn't have asked for better support than what they gave not only C but us. They were conscious of how it was impacting on us and we'd have meetings down there ... we were always included in anything even though C was an adult ... Like when she had the ECT treatment and when she went into the psychiatric unit they would always talk that through with us first.

”

Marc, metropolitan Victoria, caring for his child

The support needs of care-givers

Participants reached out to various types of support for help in their caring roles. Many people sought information online, accessed support groups, found informal support from friends, or individual psychological support. Most people were very keen to educate themselves as much as possible in order to better support the unwell person.

“

I think engaging with a psychologist one on one in terms of dealing with the trauma and grief and the second thing I think was learning ... Yeah, so I read fact sheets galore on whatever I could sort of get my hands on. You know, just would immerse myself in as much education as I could to understand what ... first of all, what was happening and be the supportive person and also maintain the fact that, yeah, she's my daughter.

”

Amber, metropolitan New South Wales, caring for her child

“

I've got a very close family and that and I've got a number of friends and so I've got support in that sense you know, plus I've got a community on the internet that I communicate with as well you know.

”

Terry, metropolitan Victoria, caring for his child

“

I realised that we needed to be using a repertoire of strategies, that just ... you know, could be employed either every day or every week ... If you started to see that you didn't do well you could identify which of those things that you might do. You know, but right down to basic things like good nutrition, good exercise, sunshine...you know, having outings. Having good pleasant things that you can create in your own life.

”

Gen, metropolitan Victoria, caring for her child

In addition, participants discussed the value they found in talking to other people who were also caring for someone who had attempted suicide and in finding peer-led information online.

“

I do find reading other people's experiences of this helpful because I think oh my god, this just happened to me you know. So, distressing because I know exactly what they're going through but, I think it's ... cause they're often ... they often articulate things that you think oh yes, that's exactly right. You know that ... that's me you know, and it's articulated in a particular way.

”

Sally, metropolitan Victoria, caring for her partner

Many people also found support groups, both in-person and online, to be particularly beneficial in providing skills and information they could use to better support the person who was unwell. The participants reported that the groups they accessed tended to focus on the person's particular mental health diagnosis, rather than on suicide prevention, per se.

“

I was getting more information about how to behave and how to interact and how to support my son and also how to get help myself ... it was a 12 week program facilitated by people who had lived experience ... and then meeting with other families who had similar experiences and the training program itself was quite ... I learnt more from that program than 13 years of education learning and development programs.

”

Felicity, metropolitan South Australia, caring for her child

“

I found a good support group. After my daughter ... that suicide attempt and once she was well enough and she was actually back in an eating disorder unit. I found a support group for parents of children ... you know, generally adult children with mental health problems, like chronic mental health problems and I found ... that was really helpful.

”

Selena, metropolitan New South Wales, caring for her child

Although people sought information from the individual health professionals who were treating their loved one, they were often frustrated at the lack of support provided.

“

So that's why I tried to do my own research to find if there were any mental health nurses who were able to have those discussions with his family but no, nothing available. There was nothing that I could do to try and get support for his family, to help them understand his illnesses which was very difficult and left me quite isolated ...

”

Jennie, metropolitan Victoria, caring for her partner

“

Nobody's there to tell you if this is the best way and I've sat in meetings with these health professionals,

”

that I'm here to learn from you guys. I want you in the here and now to please tell me what I can do differently or more or less of and they honestly couldn't come back with anything better. So, I thought, well I'll just keep doing it the way I'm doing it ...

Shae, regional New South Wales, caring for child

However, not everyone was left in the dark when it came to the information they received from healthcare professionals. Some participants said they received useful information from people in health care settings.

“ Actually she (the health professional) sent me a link that was quite good. She said, I'm sure this has a ... well has had an impact on you and yeah, she did send me a link that was quite good. It was sort of to the point of you know, that the carer needs caring too sometimes ... ”

Boyd, metropolitan NSW, caring for a friend

Future solutions

We specifically asked participants about what they thought would help others in similar situations to themselves. This was to try and understand what types of resources or interventions might provide better support for those caring for a person who has attempted suicide. Given all the reflections noted above, many spoke about the need for better acknowledgement, information and support from the health care professionals who were treating their loved one. They discussed how this support would ideally be face-to-face and at the time of need (that is, located in a hospital).

“ Well I would definitely say that, where there are other carers of the person who's in need of support. You know ... that the parents be actually drawn into a team. That they be on a team, giving their perspective and listening to options. ”

Gen, metropolitan Victoria, caring for her child

“ What carers really need is up to date information and having a relationship with the treating team as ”

well, but because of the ridiculous mental health acts we have about consumer rights and carers don't have any, that doesn't happen. The realistic thing is, there are penalties in the current mental health act for services breaking confidentiality, therefore they just shut the carer out and there is nothing constructive a carer can do if the client is saying, I can manage this myself.

Miranda, metropolitan Victoria, caring for her child

Participants talked about the need for accessible, timely and affordable support, particularly straight after discharge or during a crisis. They also said that these services needed to be more readily available to people in rural and regional areas.



Yeah so making sure that there are services that don't just cover the metropolitan areas but the regional and remote areas too. Yeah because I mean we own a business so we could afford to come to the city to get help, but there's thousands of people down there and especially males, farming males that are suicidal that are not seeking help.



Nancy, regional Western Australia, caring for her child



Timely support when my husband is suffering intense suicide ideation. Going to the ED and having to wait 5 to 8 hours through the night before he gets to see a mental health professional is not an acceptable level of crisis support. I've never experienced greater difficulty, and these events were harmful and traumatising.



Rita, metropolitan Victoria, caring for her partner

Others talked about the need for there to be better coordination between teams and services and increased training of healthcare professionals to understand the best practices relating to confidentiality so that families are not left in the dark.



The question was ... what would I like to see? I would like to see more support for medical staff to understand confidentiality or ... so that they can share information if it's going to be supportive of better care for their patients.



Felicity, metropolitan South Australia, caring for her child

One of the most common suggested strategies to help others in a similar situation was for a staff member to be made available to care-givers and support people in order to help them navigate the system, and to provide advice about how best to support the person they are caring for.



I think actually having someone providing coordination, like care coordination and someone being the advocate and helping families work things out together rather than that falling on a family member because I suppose I feel like I was very much consumed by that and I didn't have time to process or just get my head around what had happened because someone needed to be doing all of that stuff in the background to ensure that mum was safe.



Erin, regional South Australia, caring for her parent



And it's learning the language of the system. When you're trying to navigate this, the average person doesn't know the language so they can't use the correct terminology so it doesn't sound as severe. If you don't know how to identify ... so, even having a support person that can identify the different needs of the person you're trying to support and give you the terminology that you need to fill in those assessments and go through that process and articulate exactly what you need or that person with the disability needs.



Renee, regional NSW, caring for her child



I would like to see a mental health professional in the emergency department to advocate and support on behalf of the care-giver. This advocate could help explain the system, what the terminology means, and help facilitate conversations between staff and care-giver. They could explain what happens next, take the care-giver out for fresh air, coffee, and a bite to eat. Someone to listen to the care-givers fears and questions without judgement.



Denal, metropolitan Victoria, caring for her parent



Yeah. I guess what I would've found helpful at the time would've been some more face- to-face support. So ... I just remember a ... it was a nurse manager in that area who offered me some support and listened to my concerns and gave me some advice and those sorts of things. I think that's ... that was really powerful for me at that time.



Erin, regional South Australia, caring for her parent

Summary

The qualitative data has provided a rich source of information about the day-to-day experiences of caring for someone who has attempted suicide. It should be noted that there are limitations relating to volunteer response bias and the views of the smaller interview group may not represent the views of care-givers as a whole.

That being said, this sample of participants, who provided care for someone after an attempted suicide, experienced significant impact on their lives emotionally, financially, and socially. Of particular concern was the high degree of vigilance and surveillance, as well as responsibility, people felt they must carry to prevent future suicide attempts. In addition, the participants described feelings of exclusion from healthcare professionals, as well as a lack of acknowledgement and information received from health professionals about how they should navigate their caring role. This was particularly apparent during discharge processes, when families were left to be on 'suicide watch' after the person has left acute care, often with little or no support or advice about how to best support the unwell person.

Families, friends and significant others spoke of doing the best they could under difficult circumstances, and sought information and support from private clinicians, online information and support groups. However, what they lack, and would like to see, are more opportunities for face-to-face support from people with lived experience, provided in the time of immediate need – typically during hospitalisation or in early stages post-discharge. This kind of support may help them to navigate the system and offer reassurance and certainty in providing care.

Limitations

Several limitations should be addressed when interpreting the results of this study.

Firstly, as only 10.7% of participants were male, the representativeness of these results may be limited when applied to the male population. This gendered bias is a recognised limitation within literature about suicide bereavement (Maple et al., 2014) and poses a challenge when attempting to represent the male voice.

Secondly, given the high prevalence of responses from people who have cared for a person who has attempted suicide in the last 12 months, there may be an overrepresentation of people in this subgroup. Conversely, given the digital format of this survey, people with limited access to a computer/unable to use a computer may be underrepresented in this sample.

Thirdly, it should be noted that as the recruitment of participants was carried out via SANE Australia's online networks this sample may therefore be an over-representation of this population.

Finally, as much of the data relating to the person who attempted suicide is based on the accounts of another person, there could be a response bias or inaccuracies related to this information.

Discussion

The issues experienced by care-givers who support a loved one or close friend who has attempted suicide are experienced by a multitude of people across Australia. It is an issue that does not discriminate. As evidenced within this report, these challenging and stressful experiences have profoundly negative impacts on care-givers. Forty percent of those who participated in this research indicated that the suicide attempt of the loved one they provided care for had 'a significant and devastating effect on me that I still feel'. The impact of being a care-giver was demonstrated extensively within the quantitative data which showed high levels of distress experienced by this group in comparison to the general population. The qualitative data collected as part of this research also illuminated some of these experiences.

As has been argued within this research, the voices of those who care for people who have attempted suicide must be amplified. These people should be positioned as a leading sources of expertise within this space. As demonstrated by the high participation rates in this research project, these are people who will take opportunities to have their voice heard when such an opportunity is given.

The experiences collected in this research show that more often than not, the person the participants cared for also experienced complex mental health issues. In addition, nearly two thirds of those who had attempted suicide had done so more than once. As the detail in the data suggests, care-givers are individuals with a great deal of lived-experience knowledge and, through this lived experience, they hold a great deal of expertise. The authors of this report suggest that those who have cared for a loved one who has attempted suicide must be involved in decision- making and collaboration to better inform resources and services.

There is no universal experience for care-givers, with each describing quite nuanced and specific situations. However, the impacts of caring for someone who has attempted suicide – often multiple times – is significantly and profoundly negative. The data collected provides further evidence for the concept of objective burden, including: financial strain, household disruption, increased physical responsibilities, and impaired interpersonal relations within the family and broader social network. Such an experience has ongoing and enduring impacts upon a care- giver's entire life, and affects care-givers in myriad ways. This is in addition to data that also suggests a subjective burden is also felt, including painful feelings such as shame, stigma, grief, worry and resentment (this builds upon previous research, including Grant, Ballard, & Olson- Madden, 2015; Katz, Medoff, Fang, & Dixon, 2015).

One of the contributing factors to this significant, negative impact is the frustration care-givers feel with the healthcare system. Although participants did highlight some positive aspects and experiences (supportive relationships with healthcare professionals; effective resources), interactions with the healthcare system were, more often than not, inconsistent, and the lack of ongoing help and support led to multiple instances of frustration and anger. As participants explained, these experiences can have enduring effects. These are often amplified as a result of multiple suicide attempts by their loved one,

or the complicating nature of an existing mental illness. Participants detailed how the structure of the healthcare system, and crisis care in particular, does align with the enduring and continuous reality of supporting someone who experiences suicidal ideation and attempts suicide multiple times. The enduring nature of these experiences, which are often felt more significantly after their loved one has been discharged, is often met with little, or inadequate, support. This, in turn, has the potential to disenfranchise care-givers, creating a certain amount of distrust in professional support.

Our findings also indicate that the negative effects experienced by participants endure beyond the life of the suicidal crisis (again, this builds upon existing literature, including Chessick et al., 2007). While there is no direct causation between these enduring effects and lack of support provided by healthcare professionals, it does suggest that the negative experiences participants cited in relation to their interactions with healthcare services had an ongoing detrimental and disempowering effect. When accessing support, participants said the advice healthcare professionals was often inconsistent. They described feeling concerned and frustrated when offered support they felt was inappropriate or lacking. When healthcare professionals did interact with care-givers, they were only told provided with certain details. According to participants, one of the reasons for this inconsistent communication was due to an overemphasis on confidentiality. This led to confusion, and ultimately, to negative feelings towards healthcare professionals.

This research also found that these experiences had significant impact upon the mental health of the care-givers themselves. We found that close to half of all care-givers did not reach out for any assistance or support for themselves after the attempt. For those who did, psychologists and counsellors were most common, followed by GPs, telephone helplines, psychiatrists, and social workers. People were more likely to turn to friends and family. When asked about how adequately-supported they felt in caring for the person who attempted suicide, over half of participants (56.24%) felt they were 'not at all supported' and only 18% felt they were well supported. This wide-spread feeling of a lack of support is a concern given the additional overall psychological distress that was indicated by the K10 distress scale.

One of the most consistent findings throughout this research was the fact that, according to participants, healthcare professionals engaged in little-to-no consultation with them. The lack of communication and acknowledgement by healthcare providers following the suicide attempt by a loved one, reported in previous studies (Kjellin and Ostman, 2005; Cerel et al., 2006; McLaughlin et al., 2016), is strongly supported here. Care-givers described incidents where they were not listened to or, when they were, they were not taken seriously. This may be a contributing factor to the low opinion that care-givers expressed about the healthcare received by the person who attempted suicide – only 17.8% of people rated the care as good or excellent. It appears, that despite the Fifth Mental Health and Suicide Prevention Plan's (Australian Government Department of Health, 2017) recommendation that family be involved in care, there is difficulty in translating this into practice, particularly in emergency department settings. Of particular concern is that evidence in this study indicates that families are not being supported or included in discharge-planning, and are rarely having their own healthcare needs addressed.

Missing throughout a great deal of their interactions with the healthcare system when supporting and caring for a loved one who has attempted suicide is the care-giver's own voice and acknowledgement of the important role they play in providing ongoing support. As this research found, care-givers hold a great deal of lived-experience knowledge and expertise. Many highlighted the fact that they held specific knowledge that healthcare professionals did not have access to, particularly in relation to the level of suicidality that the person was experiencing. The authors believe that by creating a more collaborative working relationship between healthcare professionals and care-givers, we will see improvements in the outcomes for people who have attempted suicide *and* in the health and wellbeing of care-givers.



I guess to have someone say, this is what we do from here and these are the different options for accessing care or services for your mom or you know, these are the supports that you can seek for yourself to help get you through this and just those sorts of things. I felt like that I didn't have the information or the skills to sort of get through that journey and I'm someone who is from a health professional background.



Erin, regional South Australia, caring for her parent

Implications

This work has begun to uncover how enormous the role of the care-giver is and how significant its ramifications can be on all aspects of the care-givers life. Care-givers themselves cite multiple approaches that could inform processes for better support themselves and the person who has attempted suicide.

Participants identified person-centred strategies as being the most helpful in the provision of care. For example, *'someone who understood what I was going through and could give some advice. Knowing what to expect next'*. They also cited the importance of being included in the treating healthcare professional's assessment of a person's support network, as noted in the following: *'Better liaison between the treating health professionals themselves, and for at least one of these people to liaise with me'*.

It is very promising to see the recent attention given to the ongoing support needs of Australians who attempt suicide through aftercare programs, such as: The Way Back Support Service, being implemented by Beyond Blue; LifeSpan, being conducted by the Black Dog Institute; and state and federal 'place based' suicide-prevention trials. However, because these interventions are restricted to particular locations, and the focus is mostly on the individual who has attempted suicide, it is concerning that the needs of families, friends and significant others who play such an important role in the ongoing care of the person at risk are not being adequately addressed.

Below are three areas of focus for future work in this area:

1. Elevate the voices of people with lived experience:

The high participation rate of this survey demonstrates that care-givers are willing to share their experiences and contribute to change. A platform must be provided in order for the voices of those who care for people who have attempted suicide to be heard. Their expertise and contribution can play an essential role in suicide prevention.

There is potential to leverage this mostly unrecognised support system as a key suicide prevention strategy, if care-givers are provided with better supports and are more fully integrated into professional healthcare systems.

Recommendation One: Increase understanding within the healthcare sector about the crucial role that families, friends and other care-givers play in supporting people after suicide attempt, with a particular focus on those with complex mental health needs. Encourage health professionals to listen, recognise and respect the expertise and experience of these care-givers.

2. Review of how services interact with care-givers:

Of particular concern is evidence collected during this study that indicated families are not being supported or included in discharge planning, and rarely have their own healthcare needs addressed.

This research suggests care-givers need to be provided easily-accessible information and resources about how to care for the person at home, and to be engaged in open dialogue, as co-designers, in the development of a discharge plan.

With the introduction of more after-care services seeking to engage with people who attempt suicide post-discharge, these and other healthcare service providers can also provide enhanced support to care-givers.

Recommendation Two: A review of the standard emergency department processes and practices after a suicide attempt in each state and territory in Australia. Care-givers must play a central role in developing recommendations for change and a clear roadmap for implementation of those changes.

Recommendation Three: A simple resource should be developed for staff in emergency departments and other healthcare settings to assist and improve how they respond to care-givers. This should provide practical information to help foster a culture of shared decision-making and collaborative engagement with care-givers to improve the care, support and treatment provided.

3. Address the lack of information for care-givers:

Care-givers need access to resources that provide holistic, practical, and accessible information at the time of crisis. For example, information that outlines the roles of peer support, community supports, emotional resilience, and provides tangible examples of how others have managed through lived experience storytelling.

Recommendation Four: The development of a care-giver resource – delivered by SANE as part of the Better Support project – that is practical, accessible and engaging.

Next steps

The current research has provided invaluable and detailed information about the experiences of the friends, family and care-givers of people who attempt suicide. It has been a crucial first phase in the Better Support project and provides strong evidence for further work in this area. The next 18 months will see SANE Australia engage further with those with lived experience, and with the suicide-prevention and healthcare sectors in order to develop, pilot and evaluate resources aimed at supporting people who are caring for someone after a suicide attempt.

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